

SUBSTANCE USE and **SIGHT LOSS**

A guide for substance use and
sight loss professionals

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In this document, orange pages contain information about substance use which will be of particular interest to sight loss professionals. Navy blue pages contain information about sight loss and will be of particular interest to substance use professionals.

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About Thomas Pocklington Trust

Thomas Pocklington Trust is a national charity dedicated to delivering positive change for people affected by sight loss.

Research is central to Pocklington's work. We fund and collaborate on social and public health research initiatives aimed at identifying practical ways to improve the lives of people with sight loss, and seek to influence the services and facilities that they use.

Pocklington's research priorities are:

- the health and wellbeing of people with sight loss
- housing and environments that support the independence of people with sight loss
- building the capacity of organisations and services that work with people with sight loss to shape research and make use of research findings.

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Scope and purpose of the Guide

This Guide is for substance use and sight loss professionals. It stems from practice concerns about how best to support people who have sight loss and who also experience problems with substances, whether they are alcohol, illegal or prescribed drugs, or a combination of them.

Given the range of substance use and sight loss services, there is no 'one size fits all' response. This guide seeks to offer introductory information and advice based on current evidence and good practice.

Its aim is to offer some practical guidance, with hints and tips on how to support people with sight loss who have problematic use of substances. It provides introductory information about the overlapping issues of sight loss and substance use and signposts to further reading and information.

The production of this guidance stems from a research project led by Manchester Metropolitan University and co-funded by Thomas Pocklington Trust and Alcohol Research UK. The full report, entitled '*Alcohol, other Drugs and Sight Loss: A Scoping Study*' by Sarah Galvani, Wulf Livingston, Hannah Morgan and Sarah Wadd can be found on the Alcohol Research UK website, along with the related Alcohol Insight No. 118.

<http://alcoholresearchuk.org/alcohol-insights/alcohol-other-drugs-and-sight-loss-a-scoping-study/>

The importance of joint working

One of the findings from that research was that services, both for sight loss and substance use, are not equipped to deal with both concerns, with professionals identifying that they often did not have the policy and practice guidance necessary to respond adequately. Professional participants felt that partnership working between sight loss and substance use services would be useful, and that developing partnership practice for training, resources and practice development was a clear way forward.

It is because of this that we have adopted a joint approach for this Guide, bringing together information for the two professional groups and highlighting mutual interest. We encourage professionals to work collaboratively whenever possible when supporting people with sight loss who have problematic substance use.

What is the relationship between substance use and sight loss?

SUBSTANCE USE

SIGHT LOSS

The relationship between substance use and sight loss is not a simple one. Some key insights which emerged from a study that combined new and existing research, are:

- Professionals reported only a small number of people experiencing both sight loss and problematic substance use at the same time. Those people presented challenges for professional practice.
- Statistics from large surveys indicate that people with sight loss drink fewer units of alcohol each week, and are more likely to abstain altogether, compared to their sighted peers.
- However, levels of risky drinking remain significant. From the survey data, almost a quarter of people with sight loss felt a need to reduce their drinking, with 10% saying that they would have liked to receive help and advice on alcohol use but did not receive it.
- There are a number of challenges for people with sight loss that might increase their vulnerability to developing problems with substance or alcohol use. These include living with chronic pain, stigma, social isolation and boredom.
- Social activities related to drinking may counter some of these challenges and their advantages need to be considered alongside their risks.
- Heavy substance use when combined with other risk factors, including smoking and poor nutrition, means that people may be at risk of conditions such as tobacco-alcohol amblyopia or toxic amblyopia, a condition where a toxic reaction in the optic nerve results in visual loss. For professionals, this means having an awareness of these higher risk combinations when carrying out substance use assessments.
- Case studies from around the world suggest alcohol and/or other drug use has caused or played a very significant role in either sudden sight loss or sight deterioration over time. Early intervention had been found to be crucial in maximising the chances of improvement in a person's sight loss.



Sight loss - some basic facts

There are 1.87 million people in the UK living with sight loss that has a significant impact on their daily lives. The majority of people experiencing sight loss are older and, as the population ages, this number is likely to increase; 77% of people with sight loss are currently over the age of 65. Age is not the only risk factor for sight loss. Other risk factors include low income, smoking, diabetes, learning disabilities and belonging to a minority ethnic group.

Most people who experience sight loss retain some sight. The extent and nature will vary according to the cause of their sight loss. People may lose central or peripheral vision, or they may experience blurred vision or blind spots. This will mean that varying provisions need to be made to make the best use of their sight; for instance some people may retain the ability to read when lighting is suitably adjusted, or they may require a mobility aid when going out.

There are two categories of certified sight loss; severely sight impaired (blind) and sight impaired (partially sighted). Once someone is certified by their ophthalmologist, they are eligible to be registered with the local authority's register of blind and partially sighted people which will entitle them to practical and financial support.

Coping with sight loss

Learning to live with the experience of sight loss can be highly distressing for some individuals and their families, especially in the early period of adjustment. Its impact on people's independence can be life-changing, as people can find themselves unable to carry out many of their usual activities, e.g. drive, read, prepare food. For some people, their sight loss can lead to significant emotional and mental distress including depression, shock, anxiety, anger and grief.

Over time, people find coping mechanisms and these may include substance use. For most, this will not be problematic use; occasional visits to the pub or restaurant, for example, can play an important part in continuing to enjoy social and community life. For some people, however, their substance use can become problematic.



Living with problematic substance use

Understanding some of the reasons why people may have developed problems with substance use can maximise empathy and minimise judgemental attitudes. This is vitally important for professionals to understand as people will be highly sensitive to negative attitudes towards them. Seeing beyond the presenting problem to the underlying causes of substance use and offering help or signposting to meet those needs can maximise the efficacy of any sight loss intervention or support.

Societal attitudes to substance use

Societal attitudes can be judgemental towards people with substance problems - they may be seen as weak willed, undeserving, and untruthful. They often face discrimination and judgemental attitudes from healthcare professionals and the public alike. The individuals concerned are aware of this and may feel ashamed and stigmatised; as a result they may try to minimise or deny the extent of their use or the problems it can cause for them.

Causes of problematic substance use

It is important to remember that people do not start life with substance use problems. While there is no single cause for people becoming problematic substance users they have often experienced stressful and traumatic life events prior to, or during, their substance use. For example, evidence shows a high rate of violence and abuse, be it domestic, sexual or childhood abuse, among people with substance problems. Some occupational groups have a culture of high levels of substance use, for example, heavy alcohol use among armed forces personnel, and evidence shows increasing concerns about older people's drinking and rates of alcohol-related harm, often stemming from boredom, loneliness, and loss (including sensory loss).

Changing behaviour

Some people do not view their substance use as a problem and it may only be perceived as problematic to the family or professionals around them. For others, a decision to change their substance use may be life-changing. People can, and do, successfully change their substance using behaviours. This is often with support from professionals, family, friends and peers. Evidence shows how important key individuals are in facilitating that change, whether family members or professionals.



SIGHT LOSS

Top tips for substance use professionals working with someone with sight loss

1. Ask people about their sight loss

Be willing to ask people about their sight loss as part of routine assessments relating to their substance use. Asking about health and wellbeing is a part of the substance use professional's job. It is important not to presume someone has good sight simply because they do not have any visible signs of sight loss, e.g. a white stick or Guide Dog. Questions might include:

- When did you last have your eyes tested?
- Is there any reason why you do not have your sight checked?
- Does anyone in your family have glaucoma?

The nature and extent of someone's sight loss is going to determine how you work with them. This may be in terms of physical access to buildings and offices, and also the accessibility of materials used when working with them, e.g. written or visual exercises that would make participation difficult.

Things to look out for

- Does the person have difficulty reading small print?
- Do they have difficulty recognising faces?
- Do they miss or overfill cups when pouring liquid?
- Do they have difficulty judging steps/stairs/kerbs?

2. Ask about the relationship between the person's substance use and sight loss

Evidence shows that substance use can be a coping mechanism for people with sight loss and/or may have played a role in their sight loss. Working with the person to reduce or stop their problematic substance use is less likely to be successful if the person is having difficulties managing, or experiencing ongoing concerns with their sight loss. Joint working may be needed with sight loss professionals.

3. Have local sight loss and eye health information available

The person may not be connected to local sight loss or disability organisations and may appreciate some support. This type of support can be very useful for people with sight loss in helping them to manage the barriers they face.

Find out who the local sight loss agencies are and ask about their range of services, referral procedures and how people can access the

service. Ideally, negotiate a two-way referral pathway between your service and the local sight loss services. The Adult UK Sight Loss Pathway shows the range of sight loss services that should ideally be on offer locally, and the pathway through them.

4. Consider accessibility

People with sight loss need information in accessible formats, e.g. large print or audio or Braille. A person with sight loss may need help from you to find their way to meeting rooms, waiting areas, or toilets, for example. Ask the person what support they would like. You may also need to act as their guide around the building, at least initially. Take advice from specialist agencies about how to work with people with sight loss to identify accessibility issues, for example, saying your name when you meet the person, addressing each person in a group by name when you talk to them in a group setting. A reliance on daylight may present further challenges and scheduling appointments during daylight hours may help people to make best use of their sight.

5. Ensure you and your services meet legal obligations

All service providers in Great Britain have responsibilities under the Equality Act 2010 to people with a range of characteristics, including disability.

A person is considered to 'have a disability' when their impairment or health condition, such as sight loss, has a 'substantial' and 'long-term' negative effect on the ability to carry out daily activities. It is unlawful to directly discriminate against a disabled person by treating them less favourably because of their disability. It is also unlawful to indirectly discriminate against a disabled person, i.e. when a policy or practice that applies to everyone disadvantages people with a particular disability.

Service providers are legally required to make changes or 'reasonable adjustments' to make their services accessible to disabled people. This can include:

- making changes to policies and procedures
- adapting the built environment
- providing auxiliary aid and services such as information in accessible formats.

SUBSTANCE USE**Top tips** for sight loss professionals working with someone with problematic substance use**1. Ask people about their substance use**

Be willing to ask people about their substance use as part of routine eye examinations or support assessments. Asking about substance use is a legitimate part of your job. It is possible that you are the first professional to ask them about their substance use. Having a brief conversation on this topic, its potential impact on eye health, and/or wider health and wellbeing, may help prevent further problems or support someone to seek specialist help if they choose.

2. Ask the right questions in the right way

Ask questions in the context of your usual assessment processes, e.g. in any part of the assessment or examination which includes questions relating to general health and wellbeing.

Guidance on assessment for alcohol use advises the following question in relation to units of alcohol consumed per day.

Women: Do you ever drink more than 6 units a day?

Men: Do you ever drink more than 8 units a day?

A unit of alcohol is 10ml or 8g of pure alcohol. This is approximately one 25ml single measure of whisky (ABV 40%), or a third of a pint of beer (ABV 5-6%) or half a standard (175ml) glass of red wine (ABV 12%). ABV is the abbreviation for Alcohol by Volume, which is a standard measure of how much alcohol is contained in a given volume of an alcoholic drink. The current number of recommended alcohol units is 2-3 per day for women and 3-4 for men.



Those who answer yes are putting themselves at potential risk of harm to their health. If the answer is yes, or maybe, follow up questions could be:

- Does drinking ever cause problems for you?
- Would you like to change your drinking?
- What help do you need to change?

For drug use there is no single question. The key questions to ask include:

- What drugs are you using?
- Does your drug use ever cause you problems?
- Would you like to change your drug use?
- What help do you need to change?

If people want to change their substance use, or they describe high levels of substance use, talk to them about specialist support services and discuss the potential risks to their sight and their wider health and wellbeing.



3. Have local alcohol and drug service information available

If people disclose problematic substance use, or state that they want to change their use, you need to be ready to respond. Find out who the local alcohol/drug agencies are and their referral procedures. Ensure information and leaflets about how people can access the services are available. Ideally, negotiate a two-way referral pathway between your service and local substance use agencies.

4. Be flexible, not judgemental, in the support you offer

There may be times when the person you are working with is intoxicated or their behaviour may be altered by their substance use. Try to arrange appointments for early in the day when they may be able to function better and discuss how their substance use may affect your work with them. Be clear about what you can and cannot do if they are intoxicated. Ensure the context for the discussion is that you want to support them and make the most of the time you have together. Importantly, discuss this with them in a supportive way, rather than a judgemental way which they may have experienced from others.

Top tips for joint working

Although findings from the scoping study on alcohol and sight loss led by Manchester Metropolitan University identified only a small number of people with both sight loss and problematic substance use, those people presented challenges for professionals' existing practice approaches. Most professionals sought ways to respond and support the person appropriately on an individual basis.

Professionals often did not have policy and practice guidance to identify possible problems and respond confidently. They felt this was an area for development, and that partnership working between sight loss and substance use services would be helpful. Developing partnership practice for training, resources and practice development is clearly a way forward:

- Invite sight loss service professionals to substance use team meetings and vice versa.
- Set up 'getting to know you' meetings to facilitate knowledge exchange.
- Ensure you have sight loss and substance use information and resources available for reference within your team.
- Adopt a person-centred and holistic service response.
- Organise shared training – local alcohol and drug services and sight loss services can offer joint training days to develop mutual understanding and working partnerships. Some statutory substance use services have external and joint training in their remit.
- Develop accessible information – local sight loss services will be able to advise on making leaflets and other resources accessible to people with sight loss.
- Develop working partnerships with sight loss organisations which can provide awareness training and skills development in recognising and responding to sight loss. Substance use teams can provide support in delivering interventions and information to assist professionals who are working with substance users.

These partnerships can become a forum for shared action and for collaborative intervention and practice.

Information on sight loss

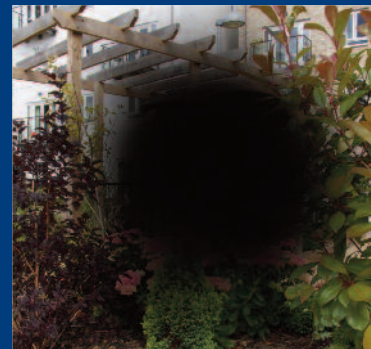
SIGHT LOSS

The effects of sight loss on people's daily lives and emotional wellbeing can be immense. Regular eye examinations by high street optometrists can identify the early stages of some eye conditions and lead to a referral to a hospital ophthalmologist for further tests, or may lead to correction through prescribed lenses or spectacles. Substance use professionals have an important role to play in encouraging take-up of regular eye examinations so that vision problems are corrected where possible.

Common conditions leading to sight loss

Different eye conditions that lead to sight loss affect different parts of the eye and optic nerve. Some of the most common conditions in the UK are outlined below. For further information on these and other less common causes of sight loss go to: www.rnib.org.uk

- **Macular Degeneration** Often called Age Related Macular Degeneration (AMD), this is most common in people aged over 65. AMD affects an area of the retina called the macula which enables us to see in detail. Often AMD presents as blurred or distorted central vision, making it difficult to see detail, and straight lines may appear to be bent or wavy. As AMD progresses it becomes increasingly difficult to undertake tasks such as reading and seeing faces. Despite retaining peripheral vision with AMD, our eyes don't have the ability to see in detail in these areas. However, maintaining this vision usually helps people get around and know 'where' things are. Some treatments can slow the effects of AMD.
- **Cataract** Cataracts are one of the most common causes of sight loss in older age. The condition may be reversed by surgery. Cataracts affect the lens inside our eye making our vision misty or cloudy. As a cataract develops, we see as if looking through a frosted window or net curtain. Bright lights cause glare or dazzle and can be hard to manage. The effects of cataract can be slow to develop and people may not realise how poor their sight has become. The risk of experiencing sight loss due to cataract is increased through ageing of the lens, as well as by some long term health conditions and some medications.



Effect of macular degeneration on a person's vision



Effect of cataract on a person's vision

SIGHT LOSS

- **Glaucoma** Glaucoma is a group of eye conditions that are related to pressures within the eye and affect the optic nerve, causing peripheral vision to be lost (sometimes called 'tunnel vision'). These changes often go unnoticed and people can lose large amounts of vision without being aware of this. As sight is lost at the edges of vision, getting out and about can be difficult and people may lose confidence. Treatments aim to prevent further damage, usually by modifying the pressure inside the eye. Lost vision cannot be restored, making regular eye examinations and early treatment very important.
- **Diabetes-related sight loss, including diabetic retinopathy** The most serious effect of diabetes on the eye is diabetic retinopathy. This affects the blood vessels at the back of the eye, which become leaky and no longer properly maintain the health of the retina. This can lead to blank patches of vision, sometimes coming and going but with the potential to lead to complete loss of sight.

Not everyone who has diabetes develops a related sight condition, though the risks increase if good diabetic control and healthy blood pressure levels are not maintained. Annual retinal screening is offered to anyone (over 12) diagnosed with diabetes and, along with regular eye examinations, is important in early detection and treatment for sight loss.
- **Retinitis pigmentosa (RP)** This group of eye disorders is almost entirely genetic and may lead to permanent changes in the retina that affect vision. Usually the first effects of RP are on the ability to see in dim light or the dark, sometimes called night blindness. It can also lead to loss of peripheral vision and glare from bright light is often a problem. All RP conditions are progressive; effects vary from person to person, and may lead to complete loss of sight. A range of treatments are being tested.



Effect of glaucoma on a person's vision



Effect of diabetic retinopathy on a person's vision

- **Neurological conditions, including head injury**

The optic nerve carries messages from the eye to the brain. Damage to the part of the brain that processes information from the optic nerve, sustained through injury or a health condition, can affect what we 'see'.

- An estimated 60% of people who survive a stroke have impaired vision in the short term and for half of them impairment lasts longer. The effects can vary, depending where in the brain the problem occurs, and may include losing part of what we can see (called hemianopia). Other effects include double vision and difficulties judging depth or distance and perceptual problems related to the cognitive effects of a stroke.
- The effects of dementia on how we perceive or understand what we see are increasingly recognised. As the dementia progresses, this begins to affect parts of the brain involved with seeing. At the same time, sight loss that may be corrected or reversed can be hidden by the symptoms of dementia.

Hallucinations

Because substance use can lead to visual hallucinations, professionals working in substance use services need to understand that sight loss rather than substance use may be the cause.

Charles Bonnet Syndrome (CBS) is the name given to visual hallucinations related to sight loss. They may occur weeks or months after loss of vision from a common eye condition and continue for some years. They vary in form from simple repeating patterns to detailed pictures of people, animals or buildings. Even when a person has little remaining useful vision, hallucinations can appear to be much clearer than normal vision. The images can last for minutes or hours and sometimes "fit" with the background, making them feel quite real, like seeing cows in a field when the field is actually empty. At other times they may appear as fantasy images.

There is no test to diagnose the cause of visual hallucinations and there is at present no single treatment that reduces or stops hallucinations associated with sight loss.

People with sight loss who experience visual hallucinations may be afraid that these are symptoms of a mental illness or another health condition. Talking about their experiences with professionals who understand the range of causes of hallucinations can be helpful.

Evidence shows that more than a third of men and a quarter of women drink above recommended alcohol levels on one day a week, while almost 9% of people aged 16-59 years report using an illegal substance in the past year. Older people's increasing use of alcohol is leading to increased levels of mental and physical harm and hospital admissions. Among these people will be individuals who have sight loss.

The effects of substance use on people will vary from person to person. People experience different effects based on factors including individual characteristics, for example, their height and weight, their tolerance to particular substances or pre-existing health conditions, e.g. heart conditions or depression. The effects of substances will also vary according to:

- the type and amount of substance taken
- the method by which it is taken
- whether it has been taken in combination with other substances, either prescribed or illegal.

The environment in which the substance is taken will also have an impact on the experience and any related risks.

Any substance taken affects the central nervous system (CNS), putting any part of the body that relies on a well functioning CNS at potential risk of damage, particularly where the substance use is frequent and excessive. There are also risks to people's health from the way people use substances: for example, blood-borne viruses may be contracted from sharing needles used for injecting drugs or from risky sexual practice with a drug-using partner.

Historically, substances have been placed into four main categories according to their impact on the CNS. These are:

1. **Depressants** - depressant drugs suppress, inhibit, or decrease some aspect of CNS activity. This group would include alcohol and benzodiazepines, for example, temazepam.
2. **Stimulants** - any drug that stimulates the CNS or enhances any neural activity. The group of drugs includes cocaine and crack, ecstasy (MDMA), amphetamine (speed).



3. **Hallucinogens** - drugs that can alter peoples' perceptions, thinking and feeling, for example, LSD, mescaline. These can include aural and visual hallucinations. Hallucinogenic experiences can also occur with other drugs including ketamine and cannabis.
4. **Opiates/opioids** - this is a group of drugs that also depress the CNS. It includes heroin, morphine, codeine and diamorphine; drugs that are often referred to as painkillers.

New psychoactive substances or 'legal highs' are increasingly available over the counter, on the internet, and on the street. They may fit into any of these classifications.

Impact of substance use

While these broad classifications provide an indication of the general impact of substances on the CNS, people might mix the substances they use and this changes any of the general effects described above.

The most reliable way of determining the effects of substances is to ask the person. They will be the expert in their own substance use and its impact. This is why routine questioning about people's use of substances is important as part of any assessment.

To summarise, substance use will have an effect on people's mental health, physical health and emotional health. It can also have an impact on their behaviour. Some people will find their substance use has positive effects, for others they will be at risk of harm. Some people may have already damaged their health as a result of their use.

An individual's problematic substance use can have a negative impact on people around them. Family relationships, social and professional networks, can be strained and damaged. However, evidence shows that positive support from family and social networks can help people to change their substance use behaviour for the better.



Key resources

Key charities and web links – sight loss

- RNIB - supporting blind and partially sighted people – Helpline 0303 123 9999 www.rnib.org.uk.
- RNIB's Sightline Directory – the directory for services aimed at helping blind or partially sighted people <https://www.sightlinedirectory.org.uk/>
- Thomas Pocklington Trust - supporting people with sight loss - www.pocklington-trust.org.uk
- Action for Blind People – providing practical and emotional advice and support across England to people who are blind or partially sighted and their friends and family. <https://actionforblindpeople.org.uk/>
- Blind Veterans - helping veterans recover their independence and discover a life beyond sight loss. <http://www.blindveterans.org.uk/>
- Guide Dogs – providing mobility and freedom to blind and partially sighted people. <http://www.guidedogs.org.uk/>
- Sense – supporting people who are deafblind www.sense.org.uk
- Disability Rights UK <http://disabilityrightsuk.org/>

Key texts, articles, reports

- Adult UK Sight Loss Pathway - provides overview of sight loss pathway through services and clear diagrams showing the range of sight loss services. https://www.rcophth.ac.uk/wp-content/uploads/2014/12/2013_PROF_252_-_Adult_UK_sight_loss_pathway.pdf

Key charities and web links – substance use

- Alcohol Concern www.alcoholconcern.org.uk
- Alcohol Focus Scotland www.alcohol-focus-scotland.org.uk
- Alcohol Concern Wales www.drinkwisewales.org.uk
- Alcohol Action Ireland <http://alcoholireland.ie/>
- Alcohol Learning Centre - www.alcohollearningcentre.org.uk
- Scottish Drugs Forum www.sdf.org.uk

- Drugs Ireland www.drugs.ie
- Wales Drug and Alcohol Helpline – 0808 808 2234, text 81066, www.dan247.org.uk
- Release – 0845 4500 215, drugs, the law and human rights - www.release.org.uk

Families and Carers

- ADFAM – An agency specialising in support and information for families and carers on alcohol and drug issues www.adfam.org.uk
- Carers UK – The voice of carers - Advice Line 0808 808 7777, www.carersuk.org

Young People

- Drinkaware –information for parents talking to their children about alcohol www.drinkaware.co.uk
- FRANK - national telephone help line 0800 776600, www.talktofrank.com
- Child and adolescent mental health services information - www.camh.org.uk

Older People

- Age UK – 0800 169 6565, www.ageuk.org.uk
- Older People and Alcohol – information leaflet <http://www.rcpsych.ac.uk/expertadvice/problemsdisorders/alcoholandolderpeople.aspx>
- Institute of Alcohol Studies (2013) Alcohol and Older People. Available online at: <http://www.ias.org.uk/uploads/pdf/Factsheets/Alcohol%20and%20older%20people%20FS%20May%202013.pdf>

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